



HR0965

LRB099 18513 GRL 42892 r

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HOUSE RESOLUTION

2 WHEREAS, Rare diseases affect almost 30 million Americans;
3 in the United States, children with rare genetic diseases
4 account for more than half of the population affected by rare
5 diseases; and

6 WHEREAS, Individuals with rare diseases experience
7 challenges that include difficulty in obtaining an accurate
8 diagnosis, limited treatment options, and difficulty finding
9 physicians or treatment centers with expertise in their
10 disease; and

11 WHEREAS, The National Organization for Rare Disorders is an
12 organization established in 1983 to provide services to and
13 advocate on behalf of patients with rare diseases; the
14 organization was a primary force behind the enactment of the
15 Orphan Drug Act and remains a critical public voice for people
16 with rare diseases; and

17 WHEREAS, The National Organization for Rare Disorders
18 sponsors Rare Disease Day to increase public awareness of rare
19 diseases; Rare Disease Day has become a global event occurring
20 annually on the last day of February, providing hope and
21 information for rare disease patients around the world; and

1 WHEREAS, Residents of Illinois are greatly affected by rare
2 diseases like Infantile Neuroaxonal Dystrophy, an extremely
3 rare genetic disorder that affects the nervous system and
4 causes a breakdown of the nerves throughout the body; and

5 WHEREAS, Infantile Neuroaxonal Dystrophy causes children
6 to unlearn skills like walking and talking and, in some cases,
7 affects their vision; most children diagnosed with Infantile
8 Neuroaxonal Dystrophy do not live to see their tenth birthday;
9 and

10 WHEREAS, Infantile Neuroaxonal Dystrophy affects about 30
11 children around the world, including Illinois resident Grace
12 Louise Herschelman, the daughter of Kyle and Mary Herschelman
13 of Hillsboro; and

14 WHEREAS, Grace Herschelman attends Hillsboro United
15 Methodist Church's preschool program 3 mornings a week; she
16 loves music, reading books, spending time with her friends, and
17 Minnie Mouse; and

18 WHEREAS, Grace Herschelman had the opportunity to go on a
19 trip to Auluani, Hawaii, which was provided by the Make-A-Wish
20 Foundation, to meet Minnie Mouse; and

21 WHEREAS, Grace's family has made her story known through

1 their blog called A Grace Filled Journey, which allows Grace to
2 touch the lives of individuals all over the world; the
3 community has become engaged in supporting research for
4 Infantile Neuroaxonal Dystrophy by supporting events such as
5 the Grace Filled Journey 5K and a one-mile run/walk event in
6 Hillsboro; and

7 WHEREAS, These events have provided Grace Herschelman and
8 her family the opportunity to raise over \$70,000 to help fund a
9 study for treatment options, as there are currently no
10 treatments or cure for those affected with Infantile
11 Neuroaxonal Dystrophy; and

12 WHEREAS, Infantile Neuroaxonal Dystrophy families around
13 the world have raised more than \$450,000 for 2 INAD studies and
14 fundraising efforts and continue to help children like Grace
15 Herschelman; therefore, be it

16 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE
17 NINETY-NINTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that we
18 join in the global observance of Rare Disease Day by
19 designating February 29, 2016 as "Rare Disease Day" in the
20 State of Illinois; and be it further

21 RESOLVED, That we recognize the courage of Miss Grace
22 Herschelman and others like her as they battle rare diseases

1 and give our wholehearted support for a State, national, and
2 global commitment to improving access to and developing new
3 treatments, diagnostics, and cures for rare diseases and
4 disorders; and be it further

5 RESOLVED, That a suitable copy of this resolution be
6 presented to Grace Herschelman as an expression of our deepest
7 admiration and respect for her and her parents' continued
8 efforts to raise awareness for Infantile Neuroaxonal
9 Dystrophy.